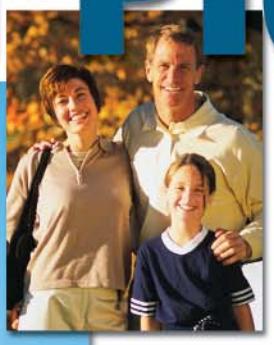
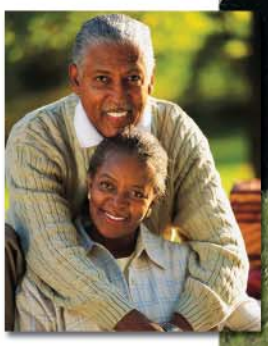
New York State

Arthritis Action Plan





Dear Colleague:

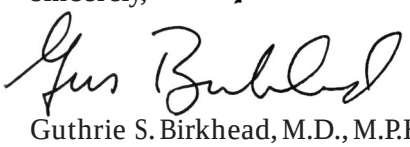
I am pleased to present the *New York State Arthritis Action Plan*. This Plan, developed by the New York State Department of Health Arthritis Program and the Arthritis Coalition, is the first of its kind to address the burden of arthritis and related diseases in New York State.

As the leading cause of disability in New York, arthritis is a major health concern. This chronic, painful disease affects about 4.7 million adults and, as the state's population ages, the numbers are only expected to increase.

The Arthritis Coalition and the NYSDOH Arthritis Program have worked diligently to produce the *New York State Arthritis Action Plan*. The Plan is modeled after the *National Arthritis Action Plan* (NAAP), which outlines three main focal areas for state-based plans. They are: Surveillance and Epidemiology, Communication and Education, and Programs, Policies and Systems. The New York Arthritis Coalition has identified strategic directions and priority goals that will guide the Plan process over the next few years.

The NYS Department of Health would like to extend a sincere thank you to all who have contributed to this important endeavor. Experts in the field of arthritis and related diseases, health care and health policy have contributed to and reviewed this Plan. As the Plan moves forward, the Arthritis Coalition invites potential partners, with an interest in arthritis prevention and control, to actively participate in upcoming activities.

Sincerely,



Guthrie S. Birkhead, M.D., M.P.H.
Director
Center for Community Health

The Mission for the Arthritis Program in the State of New York is to maximize the quality of life for New Yorkers who suffer from arthritis and its related diseases.

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I. Executive Summary

Arthritis: The Disease and its Implications

Arthritis is one of the oldest diseases known to humankind. It has been found in the mummies of Egypt and in the excavated remains of other ancient civilizations. While there are as many as 100 different types of arthritis, the most common include rheumatoid arthritis, osteoarthritis, fibromyalgia, juvenile rheumatoid arthritis and gout.

In the United States, arthritis affects nearly 70 million persons. Arthritis occurs at all ages but it is more prevalent in old age. Of persons age 65 and older, nearly half are diagnosed with the disease. Three out of five persons diagnosed with arthritis are below age 65 and 285,000 of them are children. Women age 15 years and older account for 60% of arthritis cases.

Arthritis limits activity for more than 7 million citizens with that number predicted to rise to 12% of the population by 2020. In 1999, 17.5% of all adults with a disability reported that the main health condition associated with their disability was arthritis and rheumatism. Persons with arthritis are known to have a degraded quality of life, which impacts them, their families, employers, and the healthcare system. Estimates put the total direct and indirect costs to treat persons diagnosed with arthritis and related diseases at $125 billion annually.

In New York State, arthritis affects approximately 4.7 million adult New Yorkers. Of those, 1.5 million are age 65 and older. More New York women are living with arthritis than men, with 36% of female respondents stating that they have some form of arthritis or chronic joint symptoms (2001 BRFSS). We also know that New York adults who are overweight or obese experience more arthritis than those who are not.

The Challenge

The prevalence of arthritis will increase in the US as the population ages. In 2000, a person 65 years of age had a further life expectancy of 17.9 years. This phenomenon will be complicated if the lifestyle habits of many Americans remain. As a nation, many are inactive, overweight or obese, unaware of the arthritis-injury connection, and inattentive to the risks unhealthy lifestyles create as we age.

In 1999, the Centers for Disease Control and Prevention (CDC) published *The National Arthritis Action Plan* (NAAP). The Plan describes a framework for state intervention that encourages and promotes evidence-based approaches to arthritis management. The framework describes three levels of intervention: primary, which considers weight control and injury prevention; secondary, which emphasizes early diagnosis and sound medical management; and tertiary, which focuses on self-management to reduce pain and the complications from the disease. Together with other organizations, the CDC is encouraging state public health programs to make arthritis control and prevention a priority.

The overall aims of the *National Arthritis Action Plan* are to stimulate and strengthen a nationally coordinated effort for reducing the occurrence of arthritis and to mitigate its accompanying disabilities. The Plan delineates certain goals and includes efforts to:

* Establish a solid scientific base of knowledge concerning the prevention of arthritis and related disabilities;
* Increase awareness of arthritis, its impact, the importance of early diagnosis as well as early intervention management, and effective prevention strategies.
* Implement effective programs to prevent the onset of arthritis and its related disabilities.
* Achieve the arthritis-related objectives included in Healthy People 2010. These objectives reflect benchmarks of success for measuring improvements in health and quality of life.

The New York State Arthritis Plan

In 1999, the New York State Department of Health received a three- year grant from the CDC to create an Arthritis Program. This Arthritis Plan was prepared by the New York State (NYS) Arthritis Program in cooperation with stakeholders statewide. Consistent with the guidance provided by the CDC, goals and objectives are identified in three strategic areas:

1. Epidemiology, Surveillance and Disease Prevention - document an accurate estimate of the number of people in NYS with arthritis and related diseases; publish a county specific analysis of the costs of arthritis;
2. Communication and Education - identify underserved groups who lack accurate knowledge of the nature of arthritis; increase the use of proven interventions among persons with arthritis and related diseases, their families, and health providers; develop and disseminate a broad array of material designed to reach a variety of targeted populations; and
3. Program, Policy and Systems - articulate ongoing policies that promote "best practice" methods.

The Plan incorporates a long-term time frame of five years or more with a priority sequencing of objectives based on current capacity, known or anticipated resources, successful prototype models, current needs and other environmental factors. It also acknowledges and supports the *Healthy People 2010* goals that for the first time prioritize arthritis and related diseases as important areas of policy and program focus for public health over the next decade.

The Plan is a useful guide for state and local providers, persons with arthritis and related diseases and their caregivers, health professionals and insurers, policy makers, and the general public to better understand the burden of arthritis in New York State. Importantly, the Plan describes strategies for reducing the disabling effects of the disease.

II. Overview

People are living longer. In 2000, life expectancy at 65 years was estimated to be an additional 17.9 years.[1] As one researcher put it,"...the coming of age is positive evidence...that time is a horizon that rushes toward us...."[2] But maybe not as fast as it used to. Whether this "...bounty of a lengthened life course is boon or burden for the individual and for society," this same researcher asks, is difficult to answer with certainty. He concludes,"...maybe some of both."[3]

At least 70 million Americans have been found to suffer from arthritis and its related diseases.

Death is not the only event forestalled. Marriage, for example, is occurring later as is the now more common second marriage. These multiple couplings are blending families into new, complex structures with implications for caretakers. Longevity can mean that children caretakers are becoming responsible for their parents at later points in their own lives. In 1900, for example,"...a 50 year old had only a 4 % chance of having two parents still alive; by 2000 this chance increased to 27 %, alongside an 80% chance of having at least one parent alive."[4] Put another way, to quote the journal *Generations*,"...nowadays, the majority of middle-aged people have more parents than they have children."[5]

The phenomenon of long life carries challenges for society that are neither new nor unexplored. When the baby boomer generation enters their senior years this development will become more serious. In 1940 the likelihood that a 65-year old would live to age 90 was about 7%. By 2000 the odds have more than tripled to 26%.6 Now, promoting health and preventing disease become more than ideals. They become practical goals to keep society productive and healthy. Since individual good health directly influences the collective health of the population as it ages, any significant expansion in the elderly population is noteworthy. While good fortune and good genes count, good lifestyle behaviors may count more. Proper nutrition, weight control, physical exercise and tobacco avoidance impact not only how long we live but also how well we live. Nowhere is this more compelling than in the management of chronic disease. Healthy lifestyles can prevent their occurrence or substantially reduce their complications.

The consequences of arthritis are of great concern. The intersection of the disease with longer life expectancy in the US has the potential to disable increasingly larger numbers of individuals over longer periods of time. As arthritis prevalence increases, the direct medical costs and indirect costs arising from lost productivity will also increase. This can be controlled. Effective prevention strategies and treatments exist to reduce the incidence of the disease and its related symptoms and disability. *Both the inevitability of arthritis, assumed to be an automatic byproduct of aging, as well as the belief that its physical course is irreversible, are myths.* Arthritis has become a priority for public health and for public policy leaders throughout the country. The NYS DOH Arthritis Program presents its Arthritis Plan in the spirit of this commitment to new action.

III. Background

In 1999 the *National Arthritis Action Plan:A Public Health Strategy (NAAP)* was published. Prepared under the leadership of the Arthritis Foundation, the Centers for Disease Control and Prevention (CDC), the Association of State and Territorial Health Officials and 90 other organizations, the NAAP was the last in a series of initiatives undertaken since *The National Arthritis Act* was signed into law in 1975. The Act specifically called for long range plans to address arthritis in America. In particular, the *National Arthritis Action Plan* laid the foundation for a comprehensive public health approach to reducing the burden of arthritis in the United States. The authors state in the Preface to NAAP that it is their hope "...the Plan will guide the use and organization of our nation's health resources to combat the greatest single cause of chronic pain and disability among Americans."

The NAAP describes **four key values** that underlie an integrated framework for addressing the challenge of arthritis. They are to:

- emphasize **prevention,**
- mandate the use and expansion of **the science base,**
- seek **social equity,** and
- prioritize building **partnerships.**

The *National Arthritis Action Plan* envisions a national public health strategy that will:

1. Increase public awareness of arthritis as both the leading cause of disability and important public health problem in the United States;
2. Prevent arthritis whenever possible;
3. Promote early diagnosis and appropriate management for people with arthritis to ensure that they enjoy an optimum number of years of healthy living and life;
4. Minimize preventable pain and disability due to arthritis;
5. Support people with arthritis in developing and accessing the resources they need to cope with their disease; and
6. Ensure that people with arthritis receive the family, peer and community support they need.

IV. The Burden of Arthritis

A. National Context

Arthritis and related diseases affects one out of every three persons, which is approximately 70 million people.[7] This estimate was recently revised from 48 million by the Centers for Disease Control and Prevention based on findings from the 2001 *Behavior Risk Factor Surveillance System* (BRFSS) conducted in each of the 50 states. While the BRFSS survey is conducted using randomly selected telephone numbers and depends upon self- reporting of certain symptoms, activity limitations and/or physician diagnosis, analysis of the results led the CDC to alter their previous estimates. Moreover, because prevalence of the disease has been shown to increase with age, the burden of arthritis and related diseases is expected to rise as the US population ages.

Arthritis and other rheumatic diseases are the leading cause of disability among adults in the United States, standing second only to heart disease as a cause of work-related disability.[8] Arthritis is estimated to limit daily activity for more than 7 million citizens.[9] In 1999, 17.5% of all adults with disabilities reported that the main health condition associated with their disability was arthritis and rheumatism.[10]

Persons with arthritis have substantially worse health-related quality of life than do persons without arthritis. Among adults with arthritis, the largest number of days reported as unhealthy was experienced by a cohort comprised of women, young people, and people with less than a college education. Among women and young people, this was associated with more bad "mental health" days. While depression is commonly reported and observed in people with *all* types of arthritis, it is most clearly documented among people with rheumatoid arthritis.[11]

Arthritis also has a significant effect on quality of life for family members and caregivers. At its worst, the disease progression can transform an active, productive person into a dependent individual. Arthritis potentially impacts mobility, energy level, emotional health, functional capacity and body image for the person suffering from the disease. This loss of a sense of well being and independence impacts the family dynamic and requires adjustments and compromises for everyone.

A finding of particularly serious note is that rheumatoid arthritis is associated with excess mortality. Specifically, rheumatoid arthritis can affect connective tissue and blood vessels throughout the body, triggering inflammation in a variety of organs, including the lungs and heart. This increases a person's risk of dying of respiratory and infectious diseases or of gastrointestinal disorders.[12] Rheumatoid arthritis has been linked with a higher risk of myocardial infarction in women possibly due to the inflammatory component of both diseases.[13]

Myth:
Arthritis is an old person's disease.

Fact:
Although arthritis affects one of every two persons over 65 years of age, most people with arthritis, nearly three out of five in fact, are younger than 65. *People of all ages are affected,* including children and teens. Juvenile rheumatoid arthritis is one of the most common chronic illnesses.

B. New York State Demographics

New York State is experiencing a population change driven by forces such as foreign immigration, high levels of domestic in- and out- migration, and the high fertility levels of the Baby Boom generation, which have all shaped the population of the state and will continue to do so in the future.[14] In 2000, the proportion of (23%) New York's population that was foreign born was almost twice the proportion (12%) of foreign-born residents in the nation's population.[15] Meanwhile, New York State suffered the largest number of foreign and domestic residents (1.7 million) leaving the state. These out-migrants are predominately young, educated prime work-age people and financially secure retirees.[16]

According to the 2000 Census, since 1990, the total Black or African-American population increased by 13% from 1990 to 3.2 million while the total Hispanic/ Latino population increased by 30% to 2.9 million persons. Among the state's total elderly population, minority and ethnic elderly persons will increase at the fastest rate from 20% in 1995 to 31% in 2015 and 35% in 2025.[17]

Based upon 1999 data, families who were living below the poverty level in New York totaled 535,935 or 11.5% of all families. Families with related children who are below 18 years of age numbered 418,591 or 16.9%. Individuals living below the poverty level totaled 2,692, 202 or 14.6%. Another 29.2% or 294,906 people represent families with a female householder. For persons age 65 and older who live below the poverty level in the census report, the number was 264,336 or 11.3%. Of those persons age 65 and older, 26.0% are on Social Security Income; 5.5% on Supplemental Security Income; 4.9% on public assistance and another 16.9% who reported living from retirement income.[18]

Education in the same census presented an array with 20.9 % reporting less than 9th grade education or no high school diploma; 79.1% reporting high school graduate or higher level of attainments; and another 27.4% reporting bachelor's degree or higher.

New York State's population is getting older. The 2000 Census estimates that 12.9%, or 2,448,352, of New York's population are 65. Of those, around 40% are living with a disability. Comparatively, persons between age 21 to 64 years in New York, 21.0% report a disability. Of that group, 54.1% of them are employed.[19]

The median age in New York State increased from 30.3 years of age in 1970 to 32 years of age in1980 and now exceeds 36 years. This increase is due to the aging of the Baby Boomers and the longer survival rates of the elderly. [20] By the year 2015,

the youngest of the Baby Boomers will be over 50 years old while the oldest will be approaching 70 years old. This group is projected to increase from 18 percent in 2000 to nearly 24 percent by the year 2015. Those age 70 and over will remain relatively constant at around 9 percent of the state's population.[21] The CDC projects that by the year 2025, over 55% of New Yorkers 65 and older will report having arthritis and/ or chronic joint symptoms.[22]

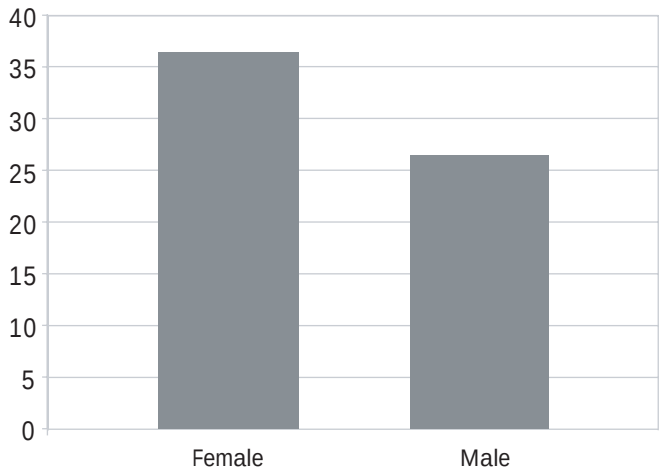
C. Prevalence of Arthritis in New York State

Using the 2001 *Behavioral Risk Factor Surveillance System* (BRFSS) data, the prevalence of arthritis among the non-institutionalized adult population in New York State was estimated to be 32%, or approximately 4.7 million people. Of this total number who self reported on the survey, 1.5 million indicated that they were age 65 and older. The group participating in the BRFSS fell into several reporting categories: 12% reported both a physician diagnosis of arthritis and chronic joint symptoms; another 11% reported based upon a physician diagnosis of arthritis alone; and a third group or 10% reported chronic joint symptoms only. Among survey respondents, there was a higher prevalence among four subsets: women, those aged 65 years and older, those considered obese, and those with less than a high school education.

Analysis of data from the New York 2001 BRFSS *Quality of Life/ Disabilities Prevention* module has shown the prevalence of limitations in activity due to arthritis to be higher among older age groups. Because increases are projected in the number and proportion of the state's older population where the incidence of arthritis is greatest, the prevalence of the disease is expected to grow. The statistics underscoring New York State's challenge mirror national data:

Figure 1

Adult New Yorkers with Arthritis by Gender

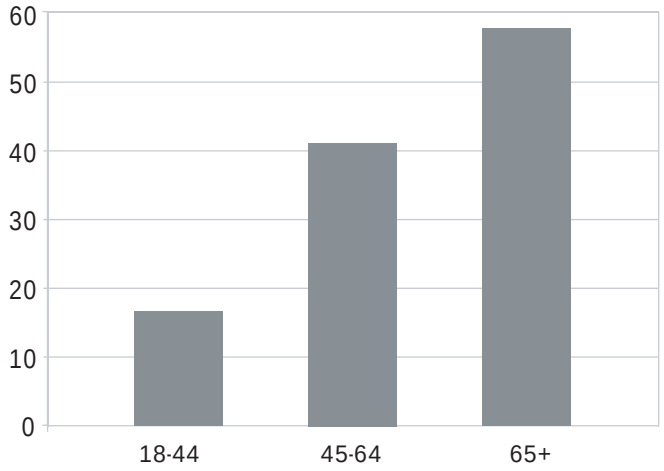


- In New York State, 36% of the 2001 BRFSS female respondents reported having some type of arthritis.

• In New York State, 59% of the 2001 BRFSS respondents who were 65 years of age and older reported having some type of arthritis.

Figure 2

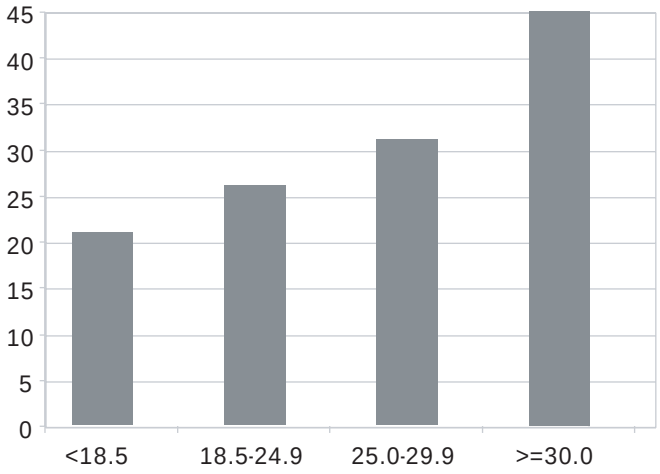
Adult New Yorkers with Arthritis by Age



• In New York State, 47% of the 2001 BRFSS respondents who were obese (Body Mass Index [BMI] of 30 or higher) reported having some type of arthritis as Figure 3 depicts.

Figure 3

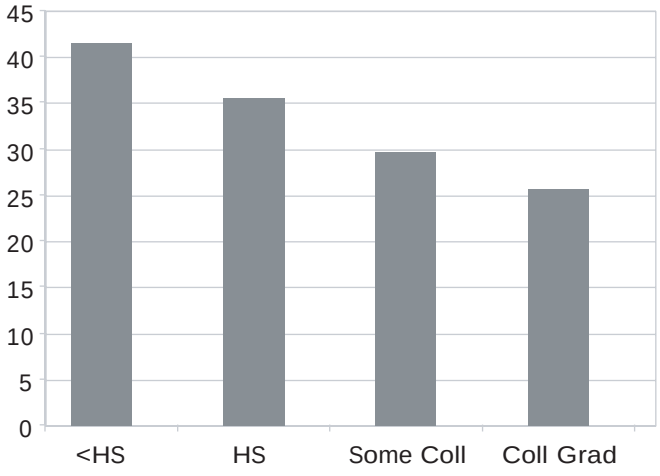
Adult New Yorkers with Arthritis by Body Mass Index (BMI)



• In New York State, 42% of 2001 BRFSS respondents who had less than a high school diploma reported having some type of arthritis.

Figure 4

Adult New Yorkers with Arthritis by Education Level



Other socioeconomic characteristics of adult New Yorkers with arthritis include race, household income, and geographical region. Of the BRFSS respondents:

- 35% were white/ non-Hispanic, 28% were black/ non-Hispanic, 26% were Hispanic, and 16% reported themselves as other/ non-Hispanic;
* 45% had a household income of $15,000 or less; and
* 34% lived outside of the New York Metropolitan area

D. Economic Costs

The Arthritis Foundation estimates the economic cost of arthritis and rheumatic diseases in the United States at nearly $125 billion dollars for the year 2000, $43 billion in direct medical costs and another $82 billion in indirect costs such as those arising from lost productivity. [23]

In a review of the literature on arthritis presented in the journal of *Arthritis and Rheumatism* in 2000 by Dunlop et al, the authors conclude that all the studies over the past two decades make the same point, namely:"...there is substantial disability associated with arthritis."[24] In this same article, the authors observe that among persons with arthritis:

* 40-70 % of them reported a work related disability;
* Almost 20% reported loss of mobility, with those rates doubling for older adults;
* 19-25% reported being unable to do their major activity; and
* 30-50% of people older than 70 years of age reported activities of daily living (ADL) limitations."[25]

In 1999, a CDC study that relied upon data from the *National Hospital Discharge Survey* reported that Arthritis was the first listed hospital discharge diagnosis and that it was associated with 744,000 hospitalizations and 44 million ambulatory visits, of which 39 million were attributed to physician offices.[26] Based on the 1993-1998 data from the *Asset of Health Dynamic Among the Oldest Old* (AHEAD) survey, a national probability sample of non-institutionalized adults aged 70 and older, the distribution of arthritis by health insurance coverage reflects the socioeconomic disparities in prevalence rates. For example, arthritis was more prevalent among people who received Medicaid plus Medicare coverage compared with people with only Medicare coverage or other supplemental insurance coverage.[27]

The New York State hospital inpatient data collected through the Statewide Planning and Research Cooperative System (SPARCS) for 2001 reported 88,401 discharges for the musculo-skeletal and connective tissue disease (MSCTD) category.Total hospital charges for this group, exclusive of physician fees, totaled $1.5 billion of which 49% were charged to Medicare or Medicaid.When looking only at discharges attributable to osteoarthritis in the same year in New York State, the total number was 26,692 with total charges of $536 million, of which 55% were charged to Medicare or Medicaid.[28] Total hip and total knee replacement discharges attributed to osteoarthritis in the same year (2001) were 9,252 and 13,631 respectively, with total charges of $203 million for hips, of which Medicare or Medicaid was charged 52%, and $ 287 million for knees, of which Medicare or Medicaid was charged 56%. [29]

V. What is Arthritis?

Arthritis encompasses over 120 diseases and conditions that affect joints, the surrounding tissues, and other connective tissues. The most common types of arthritis are osteoarthritis, rheumatoid arthritis and fibromyalgia. Other types include lupus, juvenile rheumatoid arthritis, gout, bursitis, rheumatic fever and Lyme disease to mention a few. While anyone can be at risk for developing arthritis, prevalence of this disease is higher among women than among men. Some of the more common types of arthritis are described below.

Rheumatoid arthritis is an autoimmune disease involving chronic inflammation.

The inflammation associated with rheumatoid arthritis begins in the synovial membranes and spreads to other joint tissues. Outgrowths of the inflamed tissue may invade and damage the cartilage in the joints and erode bone, leading to joint deformities. Clinical symptoms include stiffness, pain, swelling of multiple joints, commonly the small joints of the hands and wrists. Although it primarily affects the joints, rheumatoid arthritis can also affect connective tissue throughout the body and cause disease in a variety of organs, including the lungs, heart, and the eyes.

Osteoarthritis causes degeneration of joint cartilage and changes in underlying bone and supporting tissue, which leads to joint pain and stiffness, movement problems and activity limitation.

Osteoarthritis is known by many other names including degenerative joint disease, arthrosis, osteoarthrosis or hypertrophic arthritis. Osteoarthritis can affect any joint, but it commonly occurs in the hip, knees and spine. It also affects finger joints, the joint at the base of the thumb and the joint at the base of the big toe. It rarely affects the wrist, elbows, shoulders, ankles or jaw, except as a result of unusual stress or injury.

Fibromyalgia is a pain syndrome involving muscle and muscle attachment areas. Common symptoms include widespread pain throughout the muscles of the body, fatigue, sleep disorders, headaches, and irritable bowel syndrome.

Myth:
Arthritis is an inevitable part of aging.

Fact:
If this were true, most older adults and no children, would have arthritis. However, nearly half of the elderly population never experiences these conditions. And, an estimated 285,000 children are affected.

Gout is one of the few types of arthritis where the cause is known. It results from deposits of needle-like crystals of uric acid in the connective tissue, joint spaces, or both. Uric acid is a byproduct of the breakdown of purines or waste products in the body. Normally uric acid breaks down in the blood and is eliminated in urine. When the body increases its production of uric acid or if the kidneys do not eliminate enough uric acid from the body, levels build up. This is called hyperuricemia and is neither a disease nor considered dangerous. On the other hand, if excess uric acid crystals form as a result of hyperuricemia, gout can develop.

Lupus is a disorder of the immune system known as an autoimmune disease. In autoimmune diseases, the body harms its own healthy cells and tissues. This leads to inflammation and damage to various body tissues and organs. Lupus can affect many parts of the body, including the joints, skin, kidneys, heart, lungs, blood vessels, and brain. It is characterized by periods of illness, called flares, and periods of wellness, or remission. Symptoms include extreme fatigue, painful or swollen joints (arthritis), unexplained fever, skin rashes, and kidney problems. There is no cure for lupus.

Juvenile Rheumatoid Arthritis (JRA) is the most common form of arthritis in children. It may be a mild condition that causes few problems over time, but it can be much more persistent and cause joint and tissue damage in other children. JRA can produce serious complications in more severe cases. The most common features of JRA are joint inflammation, joint contracture (stiff, bent joint), joint damage and/or alteration or change in growth. Other symptoms include joint stiffness following rest or decreased activity level (also referred to as morning stiffness or gelling), and weakness in muscles and other soft tissues surrounding the involved joints. However, because JRA affects each child differently, a child may not experience all of these changes. Children also vary in the degree to which they are affected by any particular symptom.

A. Risk Factors

• Non-Modifiable Risk Factors

Certain risk factors for arthritis are considered to be non-modifiable. They include gender, age and genetic predisposition as detailed below.

Myth:
There aren't any risk factors for arthritis.

Fact:
There are a number of modifiable and non-modifiable risk factors. Modifiable risk factors for arthritis include weight, a sedentary lifestyle, and low level of education while non-modifiable risk factors include gender, age, and genetic predisposition.

1. Gender

Nationally, women age 15 years and older, account for 60% of arthritis cases. During 1989-1991, arthritis was the most common self-reported chronic condition and cause of activity limitation among women age 15 and older.[30] Among people with osteoarthritis, patterns of joint involvement also demonstrate differences among the sexes, with females on average having more joints involved and more frequent complaints of morning stiffness and joint swelling. [31]

2. Age

Half of the elderly population of the United States is affected by arthritis and the risk of developing arthritis increases with age. Self-reported arthritis increases directly with age for women, with 8.6 % of women ages 15-44, 33.5 % for women aged 45-64, and 55.8 % for women aged 65 or older reporting symptoms. [32] Prevalence rates of rheumatoid arthritis are two to three times greater among females than males. [33] Osteoarthritis is more common among males than females under age 45 and more common among females than among males after the age of 54.[34]

3. Genetic Predisposition

Research indicates that certain genes may be associated with the development of some forms of arthritis, such as rheumatoid arthritis and lupus.[35]

Groups at high-risk of osteoarthritis include:

- females with the syndrome of bony nodes usually in the joints of the fingers;
- people with congenital or developmental diseases of bones and joints (congenital hip subluxation and ipsilateral hip osteoarthritis);

- people with prior inflammatory joint disease (gout or rheumatoid arthritis); and
- people with metabolic diseases (hyperparathyroidism, hypothyroidism and chrondocalcinosis). [36]

The exact role of genetics and its interaction with other factors has not been determined.

• Modifiable Risk Factors

Certain other conditions may predispose the risk of developing arthritis but offer the greatest opportunity for prevention if avoided or overcome through simple and sustained interventions:

1. Overweight/ Obesity

Maintaining an appropriate weight or reducing weight to a recommended level lowers a person's risk for some forms of arthritis. Obesity is a major risk factor for the development and progression of osteoarthritis of the knee and is associated with an increased prevalence of hip osteoarthritis.37 Obesity is a strong risk factor for both sexes with respect to unilateral and bilateral knee osteoarthritis. 38 It is estimated that obesity accounts for 19% of osteoarthritis of the knees. [39]

In longitudinal studies, obesity predicts the development of knee osteoarthritis in both sexes. [40] An increase in weight is significantly associated with increased pain in weight-bearing joints while weight loss has been proven to decrease the risk of developing symptomatic knee osteoarthritis in women. [41] In one study, women who lost as little as 11 pounds reduced their risk of developing osteoarthritis of the knee by half. [42] Obesity is also a risk factor for gout in men. [43]

2. Inactivity

Although regular physical activity is associated with physical and mental health benefits,[44] an estimated 29% of New York adults are inactive during their leisure time. Evidence indicates that people with arthritis are less physically active and less physically fit than their peer group. [45] Furthermore, being inactive may increase arthritis problems. An appropriate exercise program is very important for people with arthritis. Physical symptoms of arthritis include pain, loss of joint motion, and fatigue. Because of these symptoms, people with arthritis are significantly less physically active than the rest of the adult population, even after taking their disability into consideration. This level of inactivity also puts them at risk for a variety of other diseases, including premature death, heart disease, diabetes, high blood pressure, colon cancer, overweight, depression, and anxiety. [46]

3. Low Level of Education and Lower Income

Some demographic factors, such as lower levels of education and lower income, are associated with arthritis. The mechanism by which these factors increase the risk of arthritis is not clear.

B. Prevention and Treatment

The science and research supporting prevention and treatment of arthritis and related diseases are relatively new. As has already been stated, however, much is already known concerning who is at- risk as well as what management interventions can be effectively employed for people with many forms of the disease.

People with arthritis often do not think that anything can be done to help them. They may not seek medical attention because they believe arthritis is an inevitable consequence of aging. To the contrary, there are many strategies that can be followed to prevent arthritis or to ease its debilitating effects. Arthritis prevention, for example, focuses on good nutrition and moderate physical activity to maintain a healthy body weight. Precautions should be taken to avoid repetitive joint use, and sport and work-related injuries.

For those living with arthritis, proper diagnosis by a health care professional is a key component of effective treatment. Fundamental interventions include good nutrition and moderate physical activity. In the area of physical activity, three types of exercises are beneficial to people with arthritis. They include range-of-motion, strengthening, and endurance exercises. In other areas, there are many arthritis medications that have been successful in reducing the pain and inflammation associated with the disease. Other treatment recommendations include rest at appropriate times, heat or cold therapies, devices such as splints and braces, and surgery when indicated.

The *Arthritis Self- Help Course* (ASHC) is a form of self-management. The course was designed to help people with arthritis change their activities and abilities, decrease their pain, and develop more self-confidence in being their own caregivers. It expands an individual's knowledge of arthritis, providing the skills to manage the disease and function as independently as possible. The success of the program is widely recognized for certain benefits. ASHC has been proven to reduce arthritis pain by 20% and physician visits by 40%. Its impact is still limited however. Currently, the ASHC program reaches only an estimated 1 % of the population of persons affected by arthritis.

Myth:
There is nothing that a person can do for arthritis.

Fact:
Some forms of arthritis, e.g. osteoarthritis of the knee, can be prevented. Although no "magic bullet" exists, research shows that early diagnosis and appropriate management can help reduce the consequences associated with many types of arthritis. Medication, physical activity, and surgery are effective interventions that make a difference. One intervention in particular, the *Arthritis Self-Help Course* (ASHC), has been shown to reduce pain by 20% and physician visits by 40%.

VI. The NYS Arthritis Program

A. History

The NAAP Arthritis Plan Framework

1 Surveillance, Epidemiology, and Prevention Research;

2 Education and Communication; and

3 Programs, Policies and Systems.

The New York State Department of Health (NYS DOH) Arthritis Program was created when National Arthritis Action Plan (NAAP) funds were granted by The Centers for Disease Control and Prevention (CDC). In September 2001, NYS received a three-year, $120,000 grant for establishing the Arthritis Program. For many years prior to the creation of the Arthritis Program in New York State, the NYS Arthritis Foundation chapters had built a firm foundation of programs and services. The state Arthritis Program is now charged with assisting these NYS chapters and others involved in prevention and treatment of arthritis, to communicate information to the public about arthritis. In addition, the NYS DOH Arthritis Program seeks ways to improve the monitoring of the burden of arthritis in NYS. The state program is encouraged to follow the NAAP framework in how it organizes and carries out its statewide responsibilities.

Since its inception in the fall of 2001, the NYS DOH Arthritis Program has nurtured partnerships and other key alliances with public and private agencies concerned with arthritis and its related diseases. It has coordinated public and professional arthritis awareness activities in collaboration with the five NYS chapters of the National Arthritis Foundation, the Lupus organizations, medical providers, public health officials, people with arthritis, their families and caregivers, and other key partners. Together, these organizations have worked to develop The New York State Arthritis Plan; set of initiatives that will serve as a blueprint for NYS arthritis programming. The Arthritis Program also collaborates with the New York State Office for the Aging and the five New York chapters of the National Arthritis Foundation to bring the Arthritis Self-Help Course (ASHC) to communities across the state.

By creating a **network of community organizations** and individuals with interest in arthritis, resources can be pooled, consistent messages can be scripted and the full spectrum of the audience needing arthritis-related messages can be reached.

The NYS DOH Arthritis Program is located in the Center for Community Health, Division of Chronic Disease Prevention and Adult Health in the Bureau of Health Risk Reduction. Other chronic disease programs within the Division include Cardiovascular Health, Disability and Health, Diabetes Prevention and Control, and Injury Prevention. The Arthritis Program has formed partnerships with the other chronic disease programs to disseminate positive arthritis messages throughout the State.

B. Partnerships

Partnerships are central to the development and successful implementation of a public health strategy for arthritis as prioritized in the NAAP. Community partnerships create the opportunity to address the burden of arthritis through a variety of settings, thus promoting arthritis awareness for the entire population.

This alliance of community partners is informing planning, implementing and evaluating an effective action plan.

A wide diversity of interest and advocacy exists in the NYS Arthritis Program partnership network. Members include representatives from the public, private and voluntary sectors of the state.

C. Alliances

• Arthritis Coalition

In September 2000, an *Arthritis Coalition* was convened to discuss an arthritis plan for NYS and the CDC arthritis grant opportunity. Organizations included the New York State Association of County Health Officials, all five New York State Arthritis Foundation chapters and the newly established NYS Arthritis Program (for a complete listing of the Arthritis Coalition see Appendix A.).

• Arthritis Work Group

As a result of this gathering, the *Coalition* appointed a smaller *Work Group.* The purpose of the *Arthritis Work Group* is to contribute to the development and implementation of The New York State Arthritis Plan. The *Work Group*:

- reviews surveillance data from the *Behavioral Risk Factor Surveillance System* (BRFSS) arthritis module;
- identifies gaps in surveillance;
- discusses communication approaches to promote arthritis awareness across the State;
- conducts and incorporate the results of the needs assessments; *and*
- develops a course of action with specific priorities defined in the Plan.

Based upon the focus areas delineated in the *National Arthritis Action Plan* (NAAP), the *Work Group* has divided itself into two subcommittees comprised of Health Communication and Education and Policy and Practice.

VII. Arthritis Prevention and Care in New York State: A Review

The Arthritis Coalition developed an inventory of strengths and weaknesses in the system of care for individuals with arthritis and related diseases. The following assessment represents their review of current demographic and resource conditions, capacities and gaps evident in the New York State network at the present time.

Myth:
People with arthritis shouldn't exercise.

Fact:
It was thought for many years that if you had arthritis you should not exercise because it would damage your joints. Now research has shown that exercise is an essential tool in managing your arthritis. **Regular, moderate exercise offers a whole host of benefits to people with arthritis.** Mainly, exercise reduces joint pain and stiffness, builds strong muscle around the joints, and increases flexibility and endurance. It also helps promote overall health and fitness by giving the individual more energy, promoting better sleep, controlling weight, decreasing depression, and enhancing self-esteem. Furthermore, exercise has secondary benefits in preventing other health problems such as osteoporosis and heart disease.

A. Core Capacities and Resources

1. The Demand for Arthritis Information and Treatment is Changing

- Advocacy for needed treatment and care is increasing among people with arthritis and related diseases.
- Arthritis and related diseases will increase as baby boomers age leading to an increase in advocacy for improvements in arthritis care.
- The work of the NYS Arthritis Coalition is increasingly relevant to larger numbers of people.

2. Public Knowledge of Disease Group

- Effective self management techniques are known and available to those with the disease.
- Published arthritis and related disease information materials are available to the public.
- An increased awareness of disease prevention is present among the general public and people with arthritis.
- Lifestyle implications due to the disease are better understood.

3. Proven Programs and Interventions

- There are established education and support groups.
- There is an increase in the availability of community exercise and/or self- help programs e.g. Arthritis Self Help Course, PACE (People with Arthritis Can Exercise), Arthritis Foundation Aquatics.

4. Medical Support Inventory

- There are knowledgeable rheumatologists and other health professionals.
- HMO's encourage exercise programs and self help programs.
- Experts such as physical therapists, health specialists, orthopedists are accessible for people with arthritis.
- Managed care products have more opportunities to promote chronic disease programs, case management, education, and other disease management services to their constituents.

5. Patient Education and Diagnosis

- Diagnosis is occurring earlier due to Arthritis Foundation and Lupus organization referrals.
- Technology and effective patient education is facilitating earlier diagnosis.
- Technological advances are also improving communications.
- New medications and procedures for treatment are having positive impact.
- People are being referred increasingly to proven programs (ASHC).

6. Advocates and Strong Staff

- There are informed and interested leaders in the Arthritis Coalition.
- Volunteers and families are dedicated to support fund raising and outreach.
- Committed, concerned and talented advocates are working in their communities.
- NYS DOH Arthritis Program is making a difference.
- Arthritis Foundation and Lupus organizations publish newsletters, create action alerts, and organize advocacy networks.

Arthritis and related diseases affect **4.7 million persons** in the state of New York.

7. Visible Support

- CDC financial support established a state arthritis program.
- Volunteer-based partnerships such as the Arthritis Foundation and Lupus organizations have readily collaborated with the Arthritis Program.
- Costs of falls and fractures are stimulating legislative action to provide funding.
- Arthritis and related diseases have become a NYS priority.
- Many local community grants are awarded to community advocates and organizations such as the Arthritis Foundation and lupus organizations.

8. Collaboration

- There is considerable knowledge and experience in the Arthritis Coalition membership.
- There is a high level of cooperation and collaboration among The Arthritis Foundation, NYS Lupus organizations, DOH, and NYS Office for Aging.
- As a result of the partnerships, development of a NYS Arthritis Plan has been fulfilled.
- The Arthritis Work Group provides for opportunities to formulate new strategies, partnerships and tactics.
- There is an increase in inter-agency collaborations within NYS; both private and voluntary sectors.

B. Compelling Gaps

Within the coming decade, approximately **70 million baby boomers** will explode the need for arthritis therapy and other interventions nationwide.

1. Disease and Population Challenges

- Arthritis and related disease types are broad and complex.
- Sustaining a commitment to lifestyle change is complicated.
- Hidden diseases can mask the scope of the disease challenge.
- The diverse patient population requires a mixed, sensitive message, which varies depending on the content and venues.
- Rheumatologists are in short supply in specific areas of NYS - such as the Western and Central NY regions. Some health insurers cannot provide rheumatology services to their membership within a reasonable travel area or timeframe due to this crisis.[47]
- Perception that not all health insurers provide, or too infrequently provide, disease management services to their constituents and, of those that do so, it may be later than optimal.

2. Professional/Provider Issues

- There is documented lack of statewide access to rheumatologists - the severity of this issue is dependent upon the geographic area with a higher severity in Western and Central NY regions.[48]
- There is sometimes a lack of communication among agencies, various foundations, and organizations as well as a lack of participation, coordination and cooperation among chronic disease constituencies and other existing collaborative groups.
- Access to technology is not maximized for communication or self-diagnosis.

- There is a perceived lack of available physician time for full patient diagnosis and treatment.
- There is a lack of appreciation for the seriousness of arthritis and related diseases.
- There is a lack of data on specific arthritis or related disease types such as lupus, rheumatoid arthritis, and fibromyalgia.
- Some health professionals are unaware of patient education, programs, and services or have been outside of the "update" reach.

3. Financial Constraints

- Auto-immune disease research is nascent.
- Basic research funding for arthritis and particularly related diseases lacks a national mandate.

4. Public Perceptions Require Change

- Consistent messages are needed that the public finds memorable.
- There are under served populations, i.e. individuals with developmental disabilities, immigrants and young mothers that are not being reached with the current messages.
- Messages concerning treatment, nutrition, and safe activities can be confusing.
- There's a need to eliminate the notion that arthritis is a "normal part of aging".
- The public's limited knowledge of auto-immune and rheumatic diseases must be addressed by increasing knowledge with accurate information.

VIII. Plan Framework

Many persons with arthritis express a sense of helplessness over their disease. A common refrain heard often is "I can't do anything about it anyway." This is simply not true.

The Public Health Framework developed by the Centers for Disease Control and Prevention for state arthritis program interventions encourages public health approaches that complement traditional medical treatment, with an emphasis on prevention. Prevention strategies for arthritis can be primary with weight control and injury prevention, secondary through early medical diagnosis, reasonable access to rheumatologists, and appropriate management, or tertiary through promoting self-management to reduce pain, limit activity and moderate complications. The published Framework for state programs addresses the following components:

- **Target Population:** Persons affected by arthritis
- **Arthritis Definition:** Diagnosis of arthritis, exhibiting symptoms of arthritis or chronic joint symptoms
- **Overall Program Goal:** To increase the quality of life among persons with arthritis
- **Immediate Effects** should include an increase in:
  - awareness of the signs, symptoms, and management options of arthritis;
  - awareness of the need for early diagnosis and appropriate management;
  - use of self management as part of routine medical care for arthritis;
  - physical activity and weight control for persons with arthritis;
  - participation in self management programs among persons with arthritis.
- **Short Term Goals:**
  - increase early diagnosis and appropriate management;
  - improve self management attitudes and behaviors among persons with arthritis.
- **Long Term Goals:**
  - reduce pain and disability among persons with arthritis;
  - improve physical, psychosocial and work function for persons with arthritis;
  - establish or increase reasonable access to health care specialists in the field of rheumatology.
  - encourage the recruitment of medical students into the field of rheumatology.

IX. Strategic Directions

The New York State Arthritis Plan adopts the three action framework areas published in the *National Arthritis Action Plan* (NAAP) (1) Surveillance, Epidemiology and Prevention Research; (2) Communication and Education; and (3) Programs, Policies and Systems as strategic directions. Within each of these categories, a corresponding set of goals and objectives has been formulated to articulate future priorities for arthritis disease management in the State of New York.

The Arthritis Coalition has delineated nine priority goals, identified in ***bold italics,*** which are identified under each strategic direction that it will focus on over the course of the next 2-3 years. Notably, concentration has been placed upon health education and communication, obtaining an accurate estimate of the prevalence and cost of arthritis and related diseases in New York State, continuing the implementation of proven interventions, and policy development that emphasizes "best practice" approaches to arthritis and related diseases.

The Centers for Disease Control and Prevention (CDC) places the highest priority for initial state arthritis program efforts on increasing **the quality of life** for people with arthritis, focusing on the reduction of pain and disability.

Strategic Direction Number One:

Programs

Goal: By 2008, design and implement a protocol to evaluate NYS implementation of proven interventions such as the ASHC, PACE, and Aquatics program.

Objectives:

1. An evaluation protocol will focus on program effectiveness including behavior changes such as increase in physical activity, mood changes, and ADL accomplishments.
2. Results of the evaluation will be analyzed and disseminated to stakeholders and funding source.

Goal: By 2008, increase the number of programs that address arthritis and related diseases in both rural and urban settings.

Objectives:

1. Identify the programs that address arthritis for baseline data.
2. Target under-served areas.
3. Engage the community with creative, grassroots collaborations.
4. Identify successful models such as the "Healthy Heart" initiative.
5. Communicate with decision- makers using data to stimulate their advocacy.

NAAP Guiding Principle

"We must have a system of health services that bridges medical, voluntary, and public health agencies…community norms that **promote prevention and improved quality of life**…(and) a well trained public health workforce to implement a national arthritis prevention effort."

(Source:CDC)

6. Expand awareness of arthritis and its related diseases among young people.
7. Work across multiple programs to communicate and educate populations.
8. Leverage resource networks in creative and collaborative ways.

Goal: Through 2010, increase the number of participants in Arthritis Self Help Course (ASHC), Persons With Arthritis Can Exercise (PACE), and aquatics programs.

Objectives:

1. Identify current levels of participation as baseline data.
2. Develop additional trainers and community leaders by working with local professionals, health care specialists, staff from the YMCA and YWCA and after school program coordinators.
3. Collaborate with other agencies in under-served areas.
4. Develop an outreach plan.
5. Enlist the aid of physicians, other health professionals, and health insurers.

Goal: Through 2010, increase physical activity among people with arthritis and related diseases.

NAAP Guiding Principle

"Efforts must be expanded beyond data and communication **to modify our social systems** to deal appropriately with arthritis… We must have supportive policies to establish an environment conducive to preventive efforts."

(Source:CDC)

Objectives:

1. Increase awareness of the need for more physical activity; describe activities consistent with disease prevention and symptom moderation.
2. Identify community programs geared toward exercise, walking and other appropriate physical activities.
3. Identify stakeholders and target messages to them.
4. Distribute information on resources and access.
5. Develop additional physical activity programs based on geographic and program gaps.
6. Publish guidelines for community fitness programs to enable them to accommodate persons with arthritis.
7. Educate physicians on the importance of prescribing physical activity to patients.
8. Investigate the cost associated with patient counseling and identify reimbursement mechanisms.
9. Work with existing state and local efforts directed at physical activity and nutrition such as the NYSDOH Physical Activity and Nutrition (PAN) Program.

Goal: Through 2010, coordinate a chronic disease model that includes arthritis and related disease education, prevention, intervention, and treatment options.

Objectives:

1. Formulate and conduct a statewide needs assessment on the state of programs and services to the designated population.
2. Develop a care model and identify funding, access and ease of use.
3. Develop an alliance of organizations to advance the model.
4. Identify experts and specialists for the model program.
5. Capture support for "best practices" from stakeholder groups: public, private, and voluntary organizations, employers, insurers, health care providers, consumers, governmental representatives, and relevant industry representatives.

Strategic Direction Number Two:

Health Education and Health Communication

Goal: By 2008, persons with arthritis and related diseases and their families know, practice and support disease management behaviors.

Objectives:

1. Provide arthritis information kits to physician offices, pharmacies, health insurers, libraries, and medical and professional associations.
2. Encourage individuals with arthritis and related diseases to become advocates at home, work, and in social settings to expand the public's awareness of and identification with the disease.
3. Provide culturally sensitive educational materials in multiple literacy levels and languages to diverse ethnic populations.
4. Disseminate published, informative clinical study information.

NAAP Guiding Principle

For all audiences:

- Use factual information.
- Use correct and consistent terminology.
- Convey that something can be done about arthritis.

(Source:CDC)

Goal: By 2008, identify underserved groups lacking accurate knowledge of the nature of arthritis and related diseases and provide effective treatment interventions.

Objectives:

1. Partner with community-based organizations, providers, and health insurers to develop strategies to reach targeted populations to educate and motivate toward treatment and healthier behaviors.

Goal: Through 2010, increase the understanding of arthritis and related diseases among health providers and insurers, medical and professional associations, and other allied health professionals in NYS.

Objectives:

1. Promote the inclusion of courses on arthritis and related diseases in NYS medical school curricula.
2. Integrate Continuing Medical Education (CME) credits for physicians and allied health personnel, for arthritis and related diseases education, into provider education opportunities.
3. Provide educational information for a full range of health personnel to improve understanding of arthritis and related diseases.
4. Support best practices and effective treatments, education, and coordination of care in medical delivery systems.

Goal: Through 2010, improve the publics' knowledge about arthritis, including its prevention and treatments.

Objectives:

1. Include information on arthritis prevention and arthritis and related diseases in health education in the public schools.
2. Develop an effective "Speakers Bureau".
3. Develop linkages with corporate wellness programs.
4. Outreach to religious and social groups.
5. Design culturally sensitive, educational materials including different literacy levels and multiple languages appropriate to NYS ethnic populations.
6. Use public service announcements.
7. Use printed space on pharmacy bags for targeted messages about the disease.
8. Publish articles in health and fitness magazines.
9. Identify and partner with other organizations and programs that reach people at increased risk for arthritis and related diseases to incorporate arthritis prevention activities and behavior modification.

Goal: Through 2010, develop and disseminate published material designed to reach a variety of targeted populations in NYS (consumers, educators, physicians and other allied health professionals). Communicate that arthritis and related diseases are serious public health problems expected to impact growing numbers of persons as the population ages. Endorse effective interventions when scientific or other credible bases for these therapies exist.

Objectives:

1. Use health communication media such as print, radio, the Web, public service announcements, and community outreach to the public, e.g., sponsored forums and educational and health related presentations.
2. Explore areas of collaboration such as designating spokespersons for some messages, and collaboration on specific Arthritis Foundation campaigns.

NAAP Guiding Principle

"Health communications is designed to **increase awareness,** the first important step in changing behavior."

(Source:CDC)

Strategic Direction Number Three:

Surveillance and Epidemiology

Goal: By 2008, document a more accurate estimate of the number of people in NYS with arthritis and related diseases.

Objectives:

1. Continue to have an arthritis module in the core questions of the New York State Behavioral Risk Factor Surveillance System (BRFSS) and, if available, its expanded counterpart (E-BRFSS) as was recently accomplished in 2003. Ensure that the BRFSS and E-BRFSS modules require respondents to identify the type of arthritis or related disease they are reporting.
2. Continue to use relevant QARR data from managed care organizations as was recently accomplished in 2003.
3. Explore the relevance of other data sources such as Medicaid and hospital systems.

NAAP Guiding Principle

"Surveillance, epidemiology, and prevention research are **the scientific tools of public health**. These tools are used to obtain accurate and reliable data, identify knowledge gaps and ways to address them, and make provisions for disseminating data to appropriate people."

(Source:CDC)

Goal: Through 2010, describe people who may be at risk of developing arthritis and, especially, related diseases for the purpose of identifying risk factors and developing a better understanding of the diseases.

Objectives:

1. Work with rheumatologists to help them to identify risk factors among their patients.
2. Work with physicians (including internists, family practitioners, and pediatricians) and health insurers to identify trends and changes they are seeing in the population with arthritis and related diseases.

3. Analyze BRFSS and E-BRFSS data as published and made available.
4. Capture the racial/ ethnic characteristics of people with arthritis by utilizing existing data.

Goal: Through 2010, assess programs serving people with arthritis and related diseases to identify gaps.

Objectives:

1. Develop data from hospitals, Arthritis Foundation chapters, health insurers, other providers and advocacy groups concerning programs and services offered, numbers of persons using programs, geographic distribution of these programs, and gaps in services.
2. Work with stakeholder groups to identify other potential service providers, assess programs and services offered, numbers of persons using programs, geographic distribution of these programs, and gaps in services.

NAAP Guiding Principle

- To obtain better scientific information.
- To disseminate that information to those who need to know.
- To translate information into action.

(Source: CDC)

Goal: Through 2010, explore a statewide arthritis and, especially, related diseases database.

Objectives:

1. Explore funding and grant opportunities for the design, development and maintenance of the database.

Strategic Direction Number Four:

Prevention Research

Goal: By 2008, assess arthritis-related health issues in the work place that impact the workforce.

Objectives:

1. Partner with the Center for Health Workforce Studies at SUNY Albany.
2. Develop a plan to share the results of such an assessment

Goal: By 2008, develop evidence-based information about the effectiveness and implementation of NYS Arthritis Program activities.

Objectives:

1. Evaluate the implementation of the proven interventions (ASHC, PACE, AF Aquatics) offered by the Arthritis Program.

2. Develop evaluation plan methods and outcome indicators.
3. Identify collaborators and resources.

Goal: Through 2010, analyze arthritis and related diseases, with direct and indirect cost estimates for counties. Use Statewide Planning and Research Cooperative System (SPARCS) data.

Objectives:

1. Identify potential collaborators to conduct an economic analysis.
2. Refine objectives of data analysis in an analysis plan.
3. Seek resources to conduct analysis.

Goal: Through 2010, better understand the factors that motivate people to engage in physical activity, and apply motivational models among people with arthritis and related diseases.

Objectives:

1. Collaborate with SUNY Albany School of Public Health and others on research in this area and develop a community-based demonstration project related to physical activity.
2. Work with existing state and local efforts directed at physical activity and nutrition such as the NYSDOH Physical Activity and Nutrition (PAN) Program.

Strategic Direction Number Five:

Policy

Goal: Through 2010, policy for arthritis and related disease management integration will focus on availability, accessibility and affordability of prevention and treatment.

Objectives:

1. Identify barriers to care such as access to providers, access to health insurance, access to accurate information, and case management coordination, and steps to alleviate the barriers.
2. Capture support from stakeholders to carry out the identified action steps such as, but not limited to, enlisting health insurers to adapt relevant goals from the NYS Arthritis Plan into their medical benefit programs, networking with county

health departments, and partnering with Area Health Education Centers (AHECs) to disseminate arthritis and related disease information.

3. Emphasize components and values identified in the NAAP in the developed policies.

Goal: Through 2010, coordinate chronic disease health policy and include arthritis and related diseases.

NAAP Guiding Principle

"Structure health communication messages and health education about arthritis to reach three broad audiences: the public, people with arthritis and their families, and health professionals."

(Source: CDC)

Objectives:

1. Explore current policy of other state chronic disease programs both within NYS and in other states and identify references to arthritis and related diseases.
2. Collaborate with other NYS chronic disease programs to incorporate arthritis and related disease information into their policies, if applicable, or develop and introduce policy that incorporates other chronic diseases and arthritis.

X. Successful Outcomes

The *Arthritis Coalition* has identified the milestones they will use to measure the plan's success such as the fulfillment of The New York State Arthritis Plan goals and objectives. In order to achieve these visions of success, there are many considerations to take into account including continued federal funding of NYS Arthritis Program and, at increasingly higher levels, and ongoing financial support for arthritis education programs.

Below are some identified visions of success.

People with Arthritis Will:

- Practice self-management in greater numbers.
- Enroll in increasing numbers in physical activity programs.
- Contact the Arthritis Foundation for assistance in numbers that double yearly through 2008.
- Participate in programs such as the Arthritis Self Help Course (ASHC), People with Arthritis Can Exercise (PACE), Arthritis Foundation Aquatics Program, etc.
- Have information on how to access services for care and support.
- Have access to actual programs to help them manage their arthritis.

The General Public Will:

- Enjoy increased awareness about arthritis.
- Understand the serious implications of arthritis for themselves and their loved ones.
- Be well informed on the full body of knowledge concerning arthritis and related diseases.

Medical Practice and Research Will:

- Support research leading to improved prevention strategies.
- Encourage physicians to tell their patients "...there are many things you can do about your arthritis."

The Health Care System Will:

- Improve diagnoses and treatment for these diseases.
- Provide access to rheumatologists.
- Encourage people to seek early diagnosis for their condition.

A high measure of success will be when persons diagnosed with arthritis join with other citizens to **value and celebrate fitness** and the very real benefits that certain physical activities produce for everyone.

XI. APPENDIX A: List of Arthritis Coalition Partners

Adirondack Rural Health Network
Arthritis Foundation, NY Chapter *
Arthritis Foundation, Northeastern NY Chapter *
Arthritis Foundation, Long Island Chapter *
Arthritis Foundation, Central NY Branch *
Arthritis Foundation, Upstate Chapter *
Blue Cross Blue Shield of Utica/Watertown
Capital District Center for Independence
Capital District Physicians Health Plan, Inc.
Center for Coping
Columbia County Department of Health
Community Health and Wellness
CWA Local 1180 Retiree Division
Eastern Adirondack Rural Health Network
Fulton County Office for the Aging
Jewish Family Services of Northeastern NY
Lupus Alliance of America, Long Island Chapter *
Lupus Alliance of America, Western NY Affiliate *
Lupus Foundation of America, Marguerite Curri Chapter *
Dr. Ellen Matzkin
Lynn McKenzie-Collins, Ph.D.
Monroe County Medical Society
Dr. Ami Milton
Dr. Martin Morell
New York State Dept. of Health:

- Office of Minority Health *
- Office of Rural Health *
- Immunization Program
- Disability and Health Program *
- Healthy Heart Program
- Cancer Screening Program *
- Diabetes Control and Prevention Program *
- Office of Medicaid Management
- New York State Osteoporosis Prevention and Education Program

New York State Office for the Aging
Pharmacists Society of the State of NY
Dr. Paul Phillips
St. Vincent's Senior Health Center
Samaritan Medical Center - Watertown, Rehabilitation Services Dept.
State University at Albany, Department of Psychology
State University at Albany, School of Public Health *
Dr. James Strossberg
SUNY Upstate Medical University
Wayside Baptist Church
The Wellness Institute of Greater Buffalo and WNY
Capital Center for Independence

** Denotes Arthritis Workgroup member*

XII. APPENDIX B: Healthy People 2010 Goals

National HP 2010 Goal:

Prevent illness and disability related to arthritis and other rheumatic conditions.

Arthritis-Related Objectives

- Increase the mean number of days without severe pain among adults who have chronic joint symptoms.
- Reduce the proportion of adults with chronic joint symptoms who experience a limitation in activity due to arthritis.
- Reduce the proportion of all adults with chronic joint symptoms who have difficulty in performing two or more personal care activities, thereby preserving independence.
- Increase the proportion of adults aged 18 years and older with arthritis who seek help in coping if they experience personal and emotional problems.
- Increase the employment rate among adults with arthritis in the working-age population.
- Eliminate racial disparities in the rate of total knee replacements.
- Increase the proportion of adults who have seen a health care provider for their chronic joint symptoms.
- Increase the proportion of persons with arthritis who have had effective, evidence-based arthritis education as an integral part of the management of their condition.

Related objectives from other focus areas (where persons with arthritis are a targeted subgroup) include the following.

Nutrition and Overweight (Chapter 19)

- Increase the proportion of adults who are at a healthy weight.
- Reduce the proportion of adults who are obese.

Physical Activity and Fitness (Chapter 22)

- Reduce the proportion of adults who engage in no leisure-time physical activity.
- Increase the proportion of adults who engage regularly, preferably daily, in moderate physical activity for at least 30 minutes per day.
- Increase the proportion of adults who engage in vigorous physical activity that promotes the development and maintenance of cardio-respiratory fitness three or more days per week for 20 or more minutes per occasion.
- Increase the proportion of adults who perform physical activities that enhance and maintain muscular strength and endurance.
- Increase the proportion of adults who perform physical activities that enhance and maintain flexibility.

XIII. Progress and Accomplishments

Note: those activities indicated below with an asterisk (*) were identified by *Coalition* members as prototypes for action, or short-term goals. If successfully implemented, they will become demonstration models for certain goals and objectives found in Section IX of the Plan.

1. Health Communications Subcommittee

- The Arthritis Program Manager, sponsored by the CDC, attended a Social Marketing Conference held by the University of South Florida in June 2002.
- The *Healthy State Wellness Newsletter,* a production of the NYS Education Department, published an article on arthritis in its July 2002 newsletter, which can be found online at *www.healthystate.org.*
- In October/November 2002, an article on arthritis was written and published in the Fulton County Office for the Aging Newsletter. (*)
- In February 2003 a pilot survey of information and education needs of patients in rheumatology practices was conducted. This effort was led by the SUNY Upstate Medical Center, together with the Central New York Arthritis Foundation Chapter and the NYS Arthritis Program. The findings will provide the content for arthritis information brochures to be developed and distributed through "Rheumatology Information Boxes" placed in physician offices throughout the state. (*)
- The Capital District Physicians Health Plan (CDPHP), a large HMO in the Capital Region with membership throughout 24 counties of the state, published an article on arthritis in its member and provider newsletter in the fall of 2002.
- The Arthritis Foundation's *Sports Injury Prevention Tip Sheet* was sent to 170 school-based providers as a result of collaboration with the NYS DOH Bureau of Child and Adolescent Health in June 2002.
- An Internet web site presence has been developed for the Arthritis Program and premiered on the DOH Web site recently. It is based upon the Arthritis Information Sheet. In the future, it will expand to include more recent BRFSS data, information about the *Arthritis Self- Help Course,* and the work of the *Arthritis Coalition* and its *Work Group.*
- An arthritis article was published in the January 2003 *Medicaid Update,* a monthly publication sponsored by the Office of Medicaid Management and is distributed to all Medicaid providers throughout the state.
- The NYS DOH Arthritis Program implemented the newly developed CDC physical activity campaign called "Physical Activity: the Arthritis Pain Reliever" in Delaware and Broome counties in the spring of 2003. This campaign

included a public service announcement for radio and brochures for countertop/point of purchase displays and other forms of dissemination to the general public. (*)

- An Arthritis Program logo and acronym were developed in September 2002. The acronym is BASIC, standing for "Being Active Supports Independence and Control."These two identifiers will be used in printed and other media messages to establish name recognition consistent with marketing communication concepts.
- The Arthritis Program presented a *T2B2* (Third Thursday Breakfast Broadcast) in May 2003. *T2B2* is a production of the SUNY School of Public Health Continuing Education Program. It is a monthly satellite broadcast designed for public health and human service professionals throughout the state. In the broadcast, two presenters, a rheumatologist and an Arthritis Foundation representative addressed the diseases that encompass arthritis and provided a brief overview of the Foundation's programs.

2. Partnership/ Linkages Subcommittee

- The Arthritis Program Manager attended the Women's Health Expo at Grand Central Station in the spring of 2002. Contacts with potential coalition partners were established.
- Connections were also made within the NYS DOH Office of Rural Health. In Delaware, Otswego, Montgomery, and Schoharie counties, the Rural Health Education Network produces two radio shows.The Network is willing to host and coordinate an arthritis presentation with the Arthritis Program in the spring of 2004.The Legislative Commission on Rural Resources provided the Arthritis Program with a mailing list of rural health networks throughout the state and provided contact information for the Area Health Education Centers (AHEC) in the state.The NYS Association for Rural Health sponsored a fall conference and asked the Arthritis Program to present an exhibit for the event, which was held in November 2002.
- In Spring 2003, the Samaritan Medical Center in collaboration with Central NY Arthritis Foundation chapter trained the physical therapists from Watertown and surrounding area communities as ASHC leaders. ASHC will follow in late spring/early summer. (*)
- Suffolk County Office for the aging, Retired Senior Volunteer Program and the Arthritis Foundation in cooperation with the NYS Arthritis Program will offer ASHC programs in the county in late spring/early summer 2003. (*)
- Cooperative efforts with the Northern New England chapter of the Arthritis Foundation are in progress within a tri county area (Clinton, Essex and

Franklin). The goal is to identify the number of community programs that specifically address arthritis symptoms (i.e. ASHC, PACE, Aquatics) and begin to develop resources to fill in the gaps that are found. (*)

- CDC funds have been secured by the University of Albany School of Public Health to conduct research on how to most effectively promote physical activity among people with arthritis. (*)

3. State Plan Subcommittee

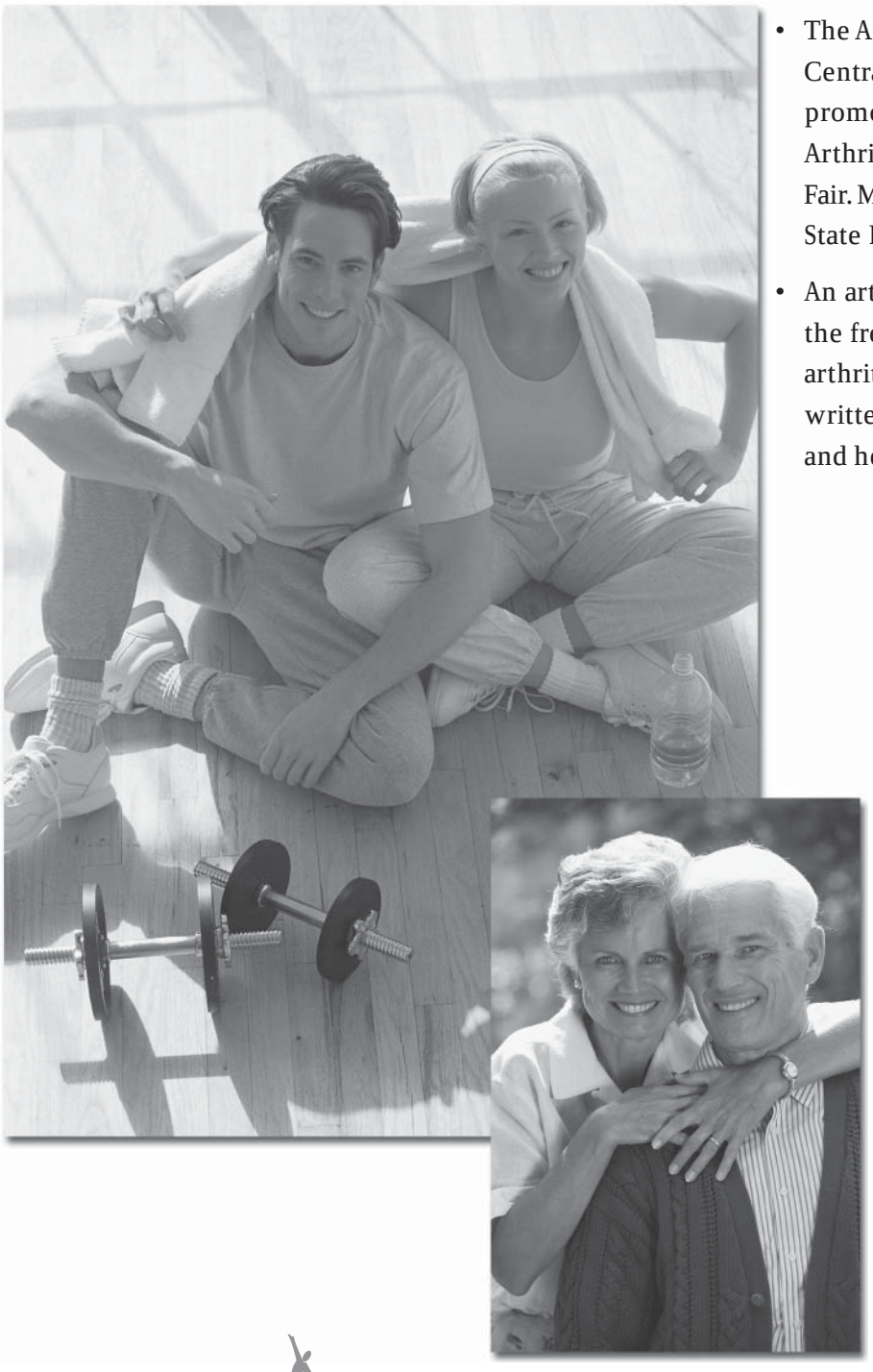
- Revision and expansion of the Needs Assessment for use with other partners such as the New York State Nurses Association was completed and will be disseminated throughout the state for a wider survey.
- A "draft" of the Arthritis State Plan was developed for the original grant application. Members of the State Plan Subcommittee of the Arthritis Coalition have reviewed that document. Their suggestions have been incorporated into the final Arthritis State Plan document.

4. Other Arthritis Program Accomplishments

- An "Arthritis Information Sheet" was developed in April 2002.
- A press release from the Governor's Office regarding the NYS Arthritis Program was distributed on April 16, 2002 and is included at the end of this Plan in the Appendix.
- The NYS DOH Summer 2002 "Media Advisory Packet" contained a variety of arthritis information materials. The packet is typically distributed to public health officials, medical centers, HMOs, special interest groups, and school nurses across the state.
- The Arthritis Work Group finalized a Mission Statement for the Arthritis Program. The mission statement will be incorporated into Arthritis Program materials as they are produced, including the Arthritis State Plan.

The Mission for the Arthritis Program in
The State of New York is to maximize
The quality of life for New Yorkers who suffer
from arthritis and its related diseases.

- The Arthritis Program, along with the Arthritis Foundation chapters of Central NY and NYC , presented an introduction of the state program and an overview of the programs and services offered by the Arthritis Foundation, to staff from the Regional DOH offices located in Syracuse and Manhattan in 2002.
- The Arthritis Program Manager actively participates in the Aging Prepared Communities Forum funded through a Hartford Foundation grant to the New York State Office for the Aging and to the University at Albany School of Social Welfare.This is a significant endeavor to develop and implement a plan to create an exemplary,“ aging prepared“ community environment in the Capital District region.



- The Arthritis Program, in conjunction with the Central NY chapter of the Arthritis Foundation, promoted the Arthritis Self -Help Course and Arthritis Fast Facts at the 2002 New York State Fair. More than 1 million people attended the State Fair last year.
- An arthritis brochure was developed to answer the frequently asked questions (FAQs) about arthritis in January 2003.This brochure is written for people with arthritis, their caregivers and health professionals.

XIV. Arthritis Foundation Needs Assessment

In order to develop a fuller understanding of the gaps facing persons with arthritis and related diseases in the state of New York, the Arthritis Program conducted a *Needs Assessment* with the five Arthritis Foundation (AF) chapters in the state in 2003. Below are the findings from this survey:

- **Consumer Barriers:** The five chapters stated that consumers reported a number of barriers. These included too few programs in specific regions of the state, insufficient time available to participate in AF programs, transportation difficulties to and from course locations, and the difficulty of successfully incorporating learned management skills and practices into every day life.
- **Chapter Barriers:** Chapters reported a number of barriers such as too few leaders and trainers in the field, not enough community partners, shortage of facilities where courses can be held (specific to Long Island), and a low volume of referrals from medical providers and allied health professionals. A corollary concern expressed by the chapters was the financial investment to pay for advertising as well as the time commitment to setup community education courses.
- **Alliances:** There is a need to identify alliances, including the New York State DOH and Office for the Aging to publicize the Arthritis Self -Help Course (ASHC) and other arthritis directed programs, disseminate relevant information, support advertising, and assist with compensation for course leaders.
- **Prevention and Early Diagnosis:** Physical activity should be promoted as a proven intervention for arthritis management; also earlier diagnosis and treatment of arthritis by physicians should be addressed.
- **Physician Outreach and Mobilization:** Rheumatologists and primary care physicians need to recognize the value of ASHC and the importance of physical activity and weight control as disease management strategies. Physician referral to the Arthritis Foundation programs should increase. Persuading the medical community to become more active partners is key.
- **Information Campaign:** Dissemination of educational materials through additional, existing health care venues such as the state chronic disease programs, county health departments, American Association for Retired Persons (AARP) and other appropriate channels would be helpful.

XV. Plan Dissemination

The mechanism for distribution of this plan will be through the NYS DOH and partner Web sites. Arthritis Coalition members may request materials for distribution to their own partners, and members of the Arthritis *Work Group* can pass along the plan to their community partners. For those organizations that maintain newsletters, mailings and web sites, ordering information will be provided to include the plan in their publications or online or both. Also the plan will be available at partner coalition meetings, the NYS Rural Health Association annual conference, and at other situations where there are opportunities for collaboration and public visibility.

XVI. Resources

The National Arthritis Action Plan

To obtain a copy of the National Arthritis Action Plan (NAAP), contact the Arthritis Foundation or the Centers for Disease Control and Prevention. Interested parties may also access the document online @ http://www.cdc.gov/nccdphp/arthritis.

The Centers for Disease Control and Prevention

National Center for Chronic Disease Prevention and Health Promotion
Mail Stop K-45, 4770 Buford Highway, NE
Atlanta, GA 30341-3717
Phone: 770-488-5464

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS)

Information Clearinghouse
National Institutes of Health (NIH)
1 AMS Circle
Bethesda, MD 20892-3675
Phone:

The Arthritis Foundation

1330 West Peachtree Street
Atlanta, GA 30309
Phone: 404-872-7100 or 800-283-7800 (toll free)

Lupus Foundation of America, Inc.

Bronx Chapter
718-822-6542

Central New York Chapter
315-454-9886 or 1-877-81-LUPUS

Genesee Valley Chapter
545-288-2910

Marguerite Curri Chapter – Utica, NY
315-829-4272 or 1-866-2-LUPUS-4

The SLE Foundation, Inc. – New York, NY

212-685-4118 or 1-800-74-LUPUS

Lupus Alliance of America

Hudson Valley NY Affiliate
914-948-1032 or 1-888-57-LUPUS

Long Island/Queens Affiliate
516-783-3370 or 1-800-850-9000

New York Southern Tier Affiliate
607-772-6522 or 1-800-33-LUPUS

Western NY Affiliate & NENY Branch
716-835-7161 or 1-800-300-4198

The NYS Arthritis Foundation Chapters

Upstate NY Chapter - Rochester
Phone: 585-264-1480

Buffalo Branch
Phone: 716-626-0333

Central NY Branch - Syracuse
Phone:315-455-8553

Long Island Chapter
Phone: 631-427-8272

NYC Chapter
Phone: 212-984-8700

Hudson Valley Office
Phone: 914-683-0842

Broome County Branch
Phone: 607-798-8048

Northeastern NY Chapter - Albany
Phone: 518-456-1203

Northern New England Chapter -(Essex, Franklin, Clinton counties)
Phone: 802-864-4988

To obtain additional copies of the **New York State Arthritis Plan** or to inquire about activities and resources for persons with arthritis, please contact the Arthritis Program Manager at the address and phone number below. *Additional information is also available at the New York State Department of Health web site at http*://www.health.state.ny.us/nysdoh/chronic/arthritis.

New York State Department of Health
Arthritis Program
150 Broadway
Riverview Center, 3W
Albany, NY 12204
Phone: 518-408-5141
arth@health.state.ny.us

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